Meaningful Involvement in Services in Health and Social Care (MISHSoC) Report

Towards an Inclusive and Effective Public and Patient Engagement Strategy for Lived Experience Populations Facing Inequality

Aim of this report:
Present research findings on service involvement in health and social care for groups who can face social exclusion.

Who was involved in this study?
- those who use *drugs and alcohol*
- those who experience *homelessness*
- those who experience *mental health* challenges
- those from *migrant, minority ethnic* and *Roma* backgrounds
- members of the *Traveller community*

National stakeholders   Service providers

What is service involvement?
Being involved in the design and development of your health and social care services and/or the policies that support their delivery at individual, organisational or strategic levels.

What we did?

9 National stakeholder interviews

35 individual interviews
7 people per group on average

2 Consultative Forums
Mix of those from interviews and discussions (28 overall) to agree priority areas and co-produce policy and practice messages.

20 Group discussions
5 discussions with service providers (39 people in total)
15 discussions with the five populations (101 people in total).

320 Service provider survey
completed surveys

10 Peer researchers projects
peer researchers conducted their own research.

Key Messages on Current Service Involvement Activity

Growth in Service Involvement

Engagement Activities of Lower Quality

Potential for Effective Service

National stakeholders highlight:

Potential for effective service involvement is recognised

Lack of progress and coordination

Complexity of the care system

Tokenistic involvement

Lack of implementation

Service provider participants report activity:

- Less at the levels of 'co-producing' (21%) or 'co-design' 23%;

- More at the middle 'engaging' level (51%)

- Or at the lower 'consulting' (37%) and 'informing' levels (35%)

- Often *uncoordinated*

- Conducted in *isolation*

- Little *impact* on decision making

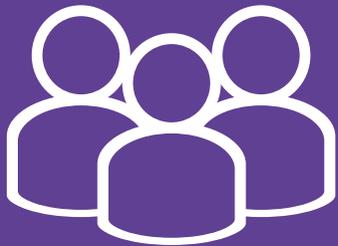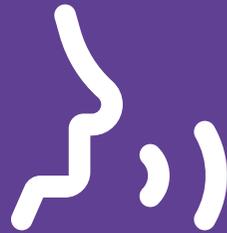## Lived experience participants, report:

- *Rarely or never been asked* for their views

- Or *not very meaningful* involvement (once-off; surveys; comment boxes)

- Being *not respected* in some services

- Being *not listened to* in some services

- Being treated in a *disempowering* way in some services

Key Messages on What Service Involvement Should Mean and Achieve

Consensus on service involvement meaning and goals for the five populations

Involvement potentially valuable for having voices heard

Lived experience participants unfamiliar with service involvement

National stakeholders and service providers:

- Involvement occurs at different levels (individual; services; organisational; national coordination)

- Involvement can include lots of activities

Values

- Understanding
- Rights
- Inclusion
- Respect
- Compassion
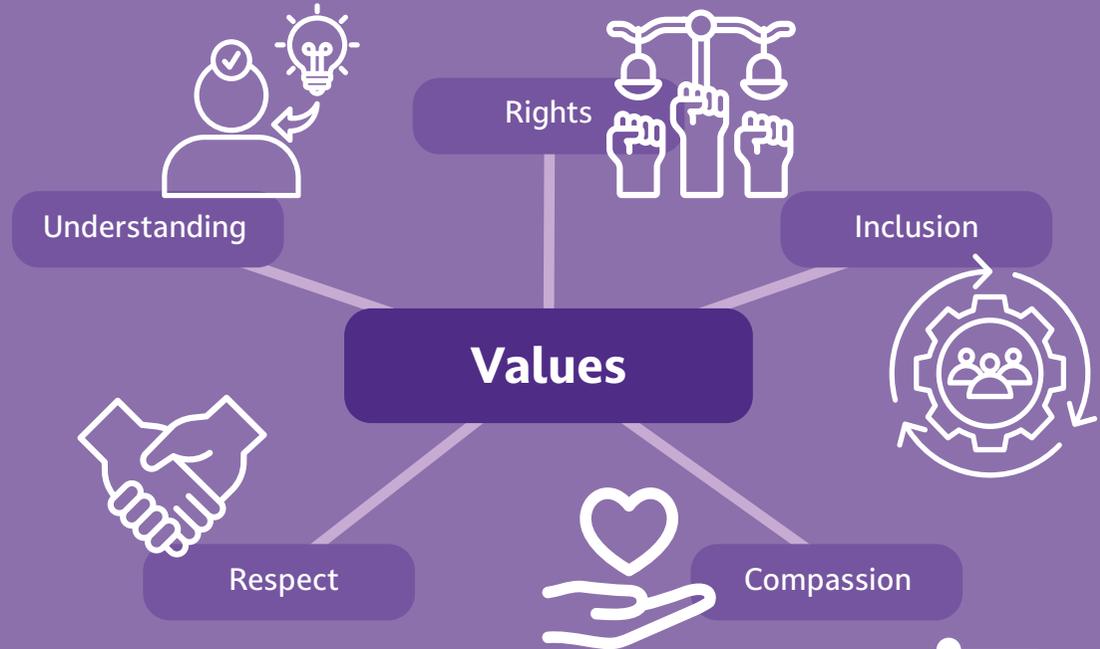
Goals

- Ensure better, more effective services
- Support better health and inclusion outcomes
- Capture unique and diverse perspectives of those with lived experience
- Make people feel listened to, valued and empowered
- Enhance cultural understanding and cultural competence
- Help inform bigger reform in service delivery
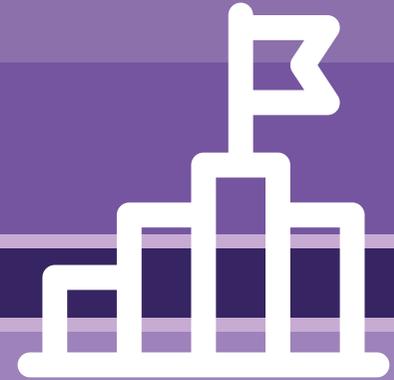
Key Messages on Service Involvement Challenges

Leadership and Commitment

- Gaps in **national direction** and **prioritisation**.
- **Deficient culture** and ethos of involvement in some organisations
- **More coordination** needed across organisations and strategies.

Implementation and Action

- **Under-resourced** (budgets; staffing; training and participant renumeration)
- **Little measurement** and **accountability**
- **Insufficient service**
- **Lack of follow** through

Population Capacities

- **Lived experience** participants bring considerable strengths
- Some may not be **psychologically ready** to **participate**
- May not have the **confidence**
- **May not be familiar** with **methods**

Trust

- **Trust** was key
- **Influenced by**:
  - **lack of trust** in **structures** and **systems**;
  - **negative experiences** of dealing with **services**.
  - **trauma-based fears**
  - **threats to privacy** and confidentiality

Representation, Stigma and Discrimination

- **Insufficient representation**, stigmatised attitudes, racism and discriminatory treatment
- **Arose from interactions**:
  - Within **society**
  - Within the **health and social care systems**.

Key Recommendations for Service Involvement

Strategic Prioritisation and Direction

Resources and Structures

Empowering and Flexible Approaches

Positive Change

Mandate

Leadership

Multi-level Implementation

Agency Flexible Design

Promote

Trust Building

Bespoke Staff Training

Increasing Awareness

Governance System

Resource Plan

Results

Communication Follow-through Action

Empathetic Culture

Challenge Discrimination

Equity

Culture of Engagement

Values and Principles